The Institute on Public Policy for People with Disabilities
375 S. Kenilworth
Elmhurst, Illinois 60126
630-915-8339
CEO- Nicole Jorwic
njorwic@gmail.com

1115 Waiver Recommendations

Although the Institute on Public Policy for People with Disabilities has concerns regarding the timeline for the 1115 waiver, we submit the following recommendations and look forward to working in partnership with the State and HMA to ensure that the implementation enriches the lives of the State's most vulnerable populations.

It is critical to evaluate the structure, design and components of the service delivery system for Individuals with Developmental Disabilities. The current system is inadequate in nearly every objective measure: the number of persons receiving services, the number of individuals on the waiting list, the range of options for residential and day services, reimbursement rates, etc.

Rate Methodology: There must be assurances that rates will not be cut for Individuals with DD, as rates are already some of the lowest in the country, between 45-50th depending on what study you look at. The 1115 waiver must be cost neutral, but that neutrality CANNOT fall on the backs of the DD Community. Historically, the ICAP has been used for eligibility determination and for the purposes of "rate setting" even though it was not designed for the latter.

The rate methodology also has not changed materially since the first waiver was approved almost two decades ago in 1989**.**The rate methodology must be adjusted to focus on the costs of direct labor, clinical supports, medical supports, transportation and other critical costs necessary to provide quality supports. Such rates should include geographical differentials and be based upon existing DOL labor and fringe costs, HUD housing costs and local transportation costs.

Employment: The waiver promotes the provision of "employment" services through large-scale congregate developmental training (DT) programs with a modest flat rate of $12,000 a year if you live in an ICFDD or $10,000 a year if you

live in your own home or in a CILA. A flat rate of $10,000 regardless of level of need, which also includes the cost for door-to-door transportation, is antiquated and insufficient to meet individual support needs. This translates into roughly $7.69 an hour for developmental training. To put this in perspective, the state-funded day care rate is currently $14,000 a year and this does not include door-to-door transportation. The waiver must adopt the State's *Employment First* policy and provide incentives for individuals to become employed through the array of employment options: competitive; supported; customized; and, individualized on-site Job supports.

Crisis: The current model in Illinois is ineffective and crisis situations usually act as a door back to Institutional settings. The waiver must include a robust crisis support system for providers, including immediate support, crisis homes, and trained teams that are available within 24 hours for individuals that don't require a change in placement. The teams must be independent and qualified.

Individualized Supports: The Illinois Home-Based Supports component of the waiver allows for individualized supports (such as a life coach, job coach, community access coach, budget coach and exercise coach), as well as budget authority to direct some or all of their supports (within established cost limits). This provision should be incorporated throughout the entire Waiver application to allow for innovation in meeting the support needs of individuals. The waiver must focus upon the individual and the broad array of necessary supports to increase the person's independence, productivity, integration, interdependence, and inclusion.

DSP wages: As the state struggles to close state operated residential facilities and to implement the *Ligas* consent decree, it is imperative that Illinois design a waiver that allows people with disabilities the dignity of choice and the provision of supports to meet their needs. This care must be provided in an environment in which direct support professionals (DSP) (since you use the acronym later, it should be consistent here) are paid a decent and livable wage. Under the current waiver, DSPs working in the Home-Based Supports program can be paid up to $20 an hour without a special review (as this rate has been indexed to annual increases in social security) However, DSPs working in a CILA or DT program, earn much less rates that has not been increased in years. Index the rates to COLA to allow for sustainable services for the future. This should be evaluated annually and adjusted each year.

Assessments: To provide truly individualized services and supports, the system must have a better tool than the ICAP to determine level of supports needed. The tool being used to do this in a number of states is the Supports Intensity Scale (SIS). Supplementary scales such as "Assessing Persons with Complex Disabilities – The KMG Fragility Scale" can be used for individuals with complex medical/health care needs. In view of the aging of the population of individuals with DD, the State also should consider using the Health Risk Screening Tool, which can be administered by

trained DSP's. This tool is web-based and available for a nominal cost per person per month. These assessments or others like them should be used to assess individuals with complex behavioral or medical needs, provide a rate based upon individual needs, and allow multiple year rates. We also suggest eliminating the 90-day review process for the add-on for individual support needs, and make that an annual reassessment.

Temporary Assistance: We recognize that temporary assistance is necessary to avoid institutionalization for individuals with I/DD in crisis. However, we strongly suggest the cap of 60 consecutive days be amended, or provisions be included so that this 60 day maximum can be waived by in cases where disruption of the temporary assistance would result in institutionalization of the individual. The waiver needs to enhance the capacity of the current crisis and emergency support system to be more effective and responsive.

Transportation: Again, the waiver should allow non-medical transportation costs to be billed through the waiver for door-to-door transport to developmental training, as an allowable cost, rather than as part of the $10,000 a year total allowable reimbursement. In Arizona their day program allows 1796 hours annually for developmental training and another 510 hours for transportation to and from home to the program.

Number of Participants: The waiver must include the over 22, 000 individuals currently on the waiting list. The State has made progress through the Ligas consent decree, but the progress has been slow. The waiver must incorporate benchmarks for lowering the list to 0.

Money Follows the Person: In a national evaluation of the Money Follows the Person Demonstration Programs (Mathematica, October 2011), it was stressed that one of the top success indicators of the MFP was the extra HCBS funding beyond what Medicaid programs typically cover. This supplement, it was found, made the difference in success rates for individuals. The Illinois waiver should allow for extra HCBS service funding as people transition from state facilities, nursing homes, and under the *Ligas* implementation plan. MFP also requires 4 or fewer people to live in one unit of housing. In Illinois, this will require changes to the waiver rates. The 75% match should motivate the state to seek new models of support, like an individual support option.

Choice: Just as individuals have a choice of CILA provider, DT provider, supported employment provider, and HBS provider, to name a few, individuals should have a choice of ISSA provider.

Residential Habilitation: There is no funding in the waiver for building maintenance. While we understand the cost of typical maintenance cannot be covered under the waiver, we are adamant the waiver should allow for repair of property destroyed as the direct result of complex behavioral challenges. If

providers are responsible for bearing the entire cost of these repairs, fewer providers will be willing, or financially able, to support individuals with complex behavioral issues.

Also in this section, it states that nursing supports like provided in an ICFDD are not allowable in the waiver. Yet in Illinois one cannot be discharged from CILA who needs ICFDD level of nursing care.

Assistive Technology: The national waiver guidelines talk about effective and cost effective technology. The Illinois waiver should better include cost effective assistive technology. CMS allows the purchase of tablets, cell phones, and GPS systems under certain circumstances. We must think in non-traditional ways about how assistive technologies can be best utilized to support individuals in their homes and communities while avoiding institutionalization.

Monitoring: The waiver should allow for the appropriate use of and payment for remote sensors and remote monitoring technology and systems to further increase the individual's control (with individual consent and rights' protections) of their housing environment and reduce the need for DSP on-site resources.

Licensure and Regulations: The State should review all of its current licensing standards and regulations to be sure that they are consistent with valued outcome measurement, while offering the necessary protections of health and life safety. Regulations should not be intrusive, nor involve a micromanaging process; rather, they should promote quality outcomes. For example, a regulation for person-centered planning should include the 5-8 key characteristics of a person-centered plan rather than 15-20 prescriptive pages of details on how to conduct a person-centered planning process. The regulations should focus on the "what" and not the "how". The how should be left to the creativity of the person/family and/or provider(s) of supports and services.

There are many corresponding issues with the Standards and Licensure Requirements for Community-Integrated Living Arrangements (CILA) that demand review in conjunction with the HCBS Waiver review.

Quality: There must be a move from a focus on process indicators to outcome measures for individuals with DD. The Bureau of Quality Management should work with providers and provide training and support. Pennsylvania's model has been recognized as a best practice by CMS and it should be considered. There should be continued transparency.

Medical Services: The CILA rate methodology discriminates against individuals with complex medical needs. If you live in a children's group home, your nursing needs are reimbursed. However, once you become an adult, the rate drops dramatically for the same individual. Current funding under CILA does not allow medical staff to be on call on a 24 hour basis, [Illinois Administrative

Code115.240 (k)], yet it is required. The 6-month medication review is unfunded. A person is only funded for one wellness visit per year. To satisfy this requirement [Administrative Code 115.240 (e)], staff must "create" an excuse for an additional doctor visit. Nurse delegation prohibitions should not be a barrier to residing in the community. Colorado, Iowa, Missouri, Nebraska, and Oregon allow 16 health maintenance tasks to be delegated, yet Illinois permits fewer than 4 tasks to be delegated, thereby increasing cost of care.

Termination of Services: Please review closely Administrative Code 115.215 (a), criteria for termination of services. The language as written does not reflect practice.

Interdisciplinary Process: The Institute supports the use of an interdisciplinary team in the development of a plan for each individual. The Administrative Code references this in section 115.230. However, discipline trained staff are not funded under the CILA program. The Individual should also be a part of the planning process and when possible individual-led ISP meetings should be the standard.

More Specific Recommendations from Members:

DHS/DRS work together to ensure continuity of supports

Some individuals require ongoing job coaching, regardless of their status with DRS. Under the current system, when DRS close an individual to their services, all employment supports provided by a community provider is not reimbursed. For individuals receiving HCBS services under the waiver, a provider agency can apply for "Alternative Day Program" funding (i.e. 39U).

- "Jane" has 2 community jobs, was closed to DRS in June 2011 and receives HCBS services. We applied for 39U funding in March of 2013 and it took until June of 2013 for us to receive the funding. During the 3 months between the time we applied for funding and the time we received the funding, we provided 115 hours of job coaching support for which we were not reimbursed
- We currently support "John" who has been closed to DRS for well over a year. He lives at home with his family and does not receive HCBS services. A job coach currently conducts twice weekly check-ins at his job site. Additionally, he receives 1:1 support with on line career development courses he takes through his employer. None of those services are reimbursed.

Employment plans and ISPs would be written (and in many cases are) to reflect the need for ongoing, uninterrupted supports.

Hours of support

There should not be a cap on the number of reimbursable hours of support someone receives in a day program. If an individual requires support to keep a job and works

more than 1100 hours in a year, the supporting agency should be reimbursed for the support it provides

Incentives for employment

- Base reimbursement on the salary and benefits paid to the individual. We currently have individuals working in corporate settings performing a variety of technology tasks who are paid a higher wage than the coaches who support them. In addition to the skills needed to support an individual with an Intellectual or developmental disability, the job coaches for these individuals are required to learn the job tasks in order to effectively support the person. DSP job coaches with the required skill set need to support individuals in these settings can be difficult to hire and retain at the current low rate of pay. We would recommend a rate that supports staff wages and benefits 40% over what the supported individual is paid in a community job.

Case management services

Reimbursement for tertiary activities not directly related to job coaching or job development, but essential to assisting individuals. Under the current system, most case management activities are not reimbursed. These include:

- completing monthly summaries
- preparing for DRS staffings and ISPs
- contact with families and individuals regarding employment issues
- processing referral packets
- scheduling job coaches for employment sites and job development classes

 Innovative day supports such as supporting micro businesses, self-employment, continuing education (post-secondary) programs such as the HALO program offered at Heartland Community College.

 Person-directed, person-controlled supports with individual budgets so that individuals are allowed to choose from a menu of supports.

 Housing not tied to supports.

 Change medication rules including care of g-tubes, insulin injections. If a person without a disability living in their home had these issues they would not have to comply with nurse practice act or DDD rules.

 Continuation of ISSA role with the focus on reviewing whether or not achievement of personal outcomes is occurring.

1. HCBS infrastructure, choice & coordination section
CONCERN: Concept paper states: "Expand access and choice of HCBS services ....based on needs and preferences rather than disability"
>We recommend inclusion of assurance that resources currently appropriated

specifically for individuals with Developmental Disabilities can not be reallocated to address other disability populations within the new waiver.
>We recommend inclusion of assurances that waiver funds will not be used as a family income subsidy rather than for services
COMMENT: Concept paper implies adding services for individuals with behavioral health challenges as a benefit to the new waiver
>We recommend inclusion of supported employment and supported housing services for individuals with Behavioral Health Challenges
>We recommend inclusion of home based services and respite care for families with children under age 18 with behavioral health challenges

2. Delivery Service Transformation section
CONCERN: Concept paper focuses on health care delivery system and health outcomes
>We are concerned that services will focus predominantly on HEDIS and other health measures rather than on social benefit indicators such as habilitation, preventative health services, employment, transportation and housing supports. We recommend inclusion of specific social outcome measures with financial incentives be included in this section to counter balance the exclusive focus on physical health.
>We recommend inclusion of language that permits providers of long terms services and supports to be eligible to become specialty "Patient-centered health homes"
>We recommend inclusion of a description of how the new waiver services would be authorized and administered (By HFS? By HCFS? By MCOS?)

3. Population Health Section
CONCERN: Concept paper focuses on health care delivery system and health outcomes
>See recommendations in #2 above.

4. Workforce Section
CONCERN: Focus on health care workers and professions fails to address the importance of improving entry and mid level workforce development (direct support workers)
> We recommend inclusion of language that addresses entry level workforce development in long term services and supports.